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14. ABSTRACT Persistent chronic pain is prevalent after a spinal cord injury (SCI), with about two-thirds of persons with SCI reporting persistent pain despite available treatments. There is a risk for a significant psychosocial impact and a substantially reduced quality of life. The primary goal of the study is to identify barriers and facilitators to coping and management of persistent pain and its impact on activities and participation after SCI. We have successfully completed administrative and other study-related tasks (e.g., database setup, training), and recruited participants consistent with our recruitment goals. The interim analysis has identified 8 overarching areas consistent with our aims and the biopsychosocial perspective of pain (i.e., pain aggravation, coping, self-remedies, experiences/attitudes to treatments & clinical trials, access to pain management, education, social environment, and pain impact). The impact that pain has on an individual's life is determined by a combination of biological factors, including injury and pain types, coping strategies and self-remedies, experiences and attitudes to treatments, access to pain treatment and information, and social environment. We are making progress towards an integrated model for living with SCI and chronic pain that considers the diversity of this population and the perceived barriers and facilitators to successful living.					
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## **INTRODUCTION:**

Persistent chronic pain is prevalent after a spinal cord injury (SCI), with about two-thirds of all persons with SCI reporting persistent pain despite available treatments. Because some of the pain types that occur after a SCI can be both persistent and severe, there is a risk for a significant psychosocial impact and a substantially reduced quality of life. Chronic pain after SCI is associated with lower general health and well-being, and with higher levels of depression. Although pain after SCI has been the topic of multiple basic and clinical research studies, the insufficient management of pain continues to be a significant problem and an important unmet need after SCI. It is clear that in order to treat pain more successfully in this population, we need to increase our understanding of not only the underlying mechanisms of these pain conditions but also how people with SCI manage to live with their pain and what their expectations and experiences are regarding barriers and facilitators to successful pain management and optimal quality of life.

*The primary goal of the study is to identify barriers and facilitators to coping and management of persistent pain and its impact on activities and participation after SCI and how this may change with time since injury.*

## **BODY:**

The narrative below is organized according to the SOW.

### **1. Training of staff and setting up data bases for Phase 1 and Phase 2 (month 0-4)**

Training of staff and investigators was initiated at the onset of the study and is a continuing effort that includes group meetings with investigators and staff regarding specific study related training, logistical issues, database setup, data analysis and training in ATLAS.ti.

### **2. IRB and regulatory work for Phase 1 and Phase 2 (month 0-4)**

All regulatory work was completed as planned.

### **3. Recruitment (month 5-36)**

**Recruitment will be a continuous process and we expect to achieve our recruitment goals based on our previous experience. Recruitment for Phase 2 will start at month 24.**

So far, we have enrolled 23 individuals with SCI and chronic pain. Two of which (#10 and #17) withdrew prior to their qualitative interviews. Demographic, pain and injury data for these participants are shown in **Tables 1, 2, and 3** on the next pages.

ID#	Sex	Age	Level of Injury (Neurological Level)	Veteran Status	ASIA Impairment Scale	Pain Medication
1	M	56	C3	Veteran	D	Gabapentin, Tramadol
2	M	48	C2	Veteran	D	Gabapentin, Tramadol
3	M	27	T8	Non-Vet	A	None
4	F	51	C6	Non-Vet	D	Gabapentin
5	M	54	C2	Veteran	A	Gabapentin, Tramadol
6	M	56	C1	Veteran	D	Gabapentin, Tramadol, Venlafaxine
7	F	35	C7	Non-Vet	A	None
8	M	32	T4	Non-Vet	A	Gabapentin, Oxycodone
9	M	22	T3	Non-Vet	A	None
11	M	68	C7	Non-Vet	A	Pregabalin, Cymbalta
12	F	38	T1	Veteran	A	Dilaudid, Morphine
13	M	54	C5	Non-Vet	D	None
14	M	29	C7	Non-Vet	B	Pregabalin
15	M	66	T5	Non-Vet	A	None
16	M	52	T10	Non-Vet	C	Gabapentin, Tramadol
18	M	46	C5	Non-Vet	A	Carbamazepine, Amitriptyline, Valium
19	M	25	T8	Non-Vet	A	None
20	F	27	T2	Non-Vet	A	Tylenol
21	F	27	C5	Non-Vet	A	Pregabalin
22	F	34	T3	Non-Vet	A	Fentanyl patch, Ibuprofen
23	M	24	C7	Non-Vet	A	Oxycodone
15 Males $\bar{X}$ age 44 yrs			6 with Paraplegia	5 Veterans	14 - A	11 on Anticonvulsant
			9 with Tetraplegia	16 Non-Vets	1 - B	9 on Narcotic/Narcotic-like
6 Females $\bar{X}$ age 35 yrs			3 with Paraplegia		1 - C	3 on Antidepressant
			3 with Tetraplegia		5 - D	1 on NSAID

*\*5 Not on Pain Medication - all ASIA-A*

**Table 1 - Participant Demographics**

ID#	Worst Pain	Intensity (0-10)	Days/Week with Pain	2 <sup>nd</sup> Worst Pain	Intensity (0-10)	Days/Week with Pain	3 <sup>rd</sup> Worst Pain	Intensity (0-10)	Days/Week with Pain
1	Neuropathic Below-level	4	7	Neuropathic At-level	2	7	Musculoskeletal	1	7
2	Neuropathic At-level	7	7	Neuropathic Below-level	7	7	Neuropathic Below-level	4	7
3	Neuropathic At-level	8	7	Neuropathic At-level	8	7	None		
4	Neuropathic At-level	9	7	Neuropathic Below-level	8	7	None		
5	Neuropathic At-level	7	4	Neuropathic Other	8	5	Neuropathic Below-level	8	5
6	Neuropathic Below-level	7	7	Neuropathic Below-level	9	7	Musculoskeletal	5	7
7	Neuropathic Below-level	9	7	Neuropathic Below-level	8	7	Neuropathic Below-level	6	5
8	Neuropathic At-level	10	7	Neuropathic At-level	7	7	None		
9	Neuropathic Below-level	5	7	Neuropathic Below-level	5	7	Musculoskeletal	2	3
11	Musculoskeletal	5	7	Musculoskeletal	4	4	Musculoskeletal	6	2
12	Neuropathic At-level	8	7	Neuropathic Below-level	8	7	None		
13	Neuropathic At-level	5	7	Musculoskeletal	3	2	Neuropathic Below-level	3	7
14	Neuropathic Below-level	8	7	Musculoskeletal	4	7	Neuropathic Below-level	8	7
15	Neuropathic At-level	5	7	None			None		
16	Neuropathic Below-level	8	7	Neuropathic-Other	6	7	Neuropathic At-level Musculoskeletal	9	7
18	Neuropathic Below-level	5	7	Nociceptive-Visceral	5	7	None		
19	Neuropathic At-level	7	7	Musculoskeletal	5	3	None		
20	Musculoskeletal	7	4	Neuropathic At-level	9	5	Neuropathic Below-level	4	7
21	Neuropathic Below-level	5	7	Neuropathic At-level	6	7	Musculoskeletal	8	2
22	Neuropathic At-level	6	7	Other	8	5	Neuropathic Below-level	5	5
23	Musculoskeletal	6	3	Musculoskeletal	5	1	None		

**Table 2 - Characteristics of the 3 Worst Pains**

ID#	Difficulty Dealing with Pain (0-10)	MPI-SCI (Selected Subscales)			Category of Pain Severity
		Pain Severity	Affective Distress	Life Interference	
		(0-6)	(0-6)	(0-6)	
1	5	2.33	1.67	2.50	Mild-Moderate
2	7	4.33	3.33	3.88	Severe
3	8	4.00	4.00	1.63	Moderate-Severe
4	8	4.33	1.33	4.38	Severe
5	6	5.67	3.33	4.13	Severe
6	7	3.33	3.67	4.13	Moderate
7	7	4.33	5.67	4.50	Severe
8	3	3.33	1.33	2.00	Moderate
9	2	1.00	3.67	1.25	Mild
11	4	3.00	2.67	1.50	Moderate
12	5	4.00	5.00	3.38	Moderate-Severe
13	0	1.67	1.00	0.00	Mild
14	5	3.33	2.67	3.88	Moderate
15	3	2.33	1.00	1.13	Mild-Moderate
16	6	5.00	3.67	2.38	Severe
18	5	2.67	1.67	1.13	Moderate
19	8	4.33	4.33	2.13	Severe
20	4	3.33	3.00	1.50	Moderate
21	5	3.33	1.67	1.75	Moderate
22	6	3.00	3.67	2.25	Moderate
23	5	2.33	1.33	2.25	Mild-Moderate

**Table 3 - Pain Summary**

#### **4. Phase 1 (month 5-28)**

This study is designed as a two-phase study, in which the first phase (n=35) will provide comprehensive and substantial in-depth insight into the experience of living with chronic pain after SCI in three sessions.

#### **Qualitative Interviews and analysis (month 5 to 24)**

After a brief phone screening to assess initial eligibility and answer questions about the study, each subject will come in for his/her first session to confirm eligibility. This session will consist of informed consent procedures, the ASIA examination, and an interview including background data collection regarding demographic factors and medical history, pain and psychosocial impact using interview-format questionnaires.

This part of the study has been completed for 21 subjects and a brief summary of these data is presented in Tables 1, 2, and 3 above).

Each participant will complete two semi-structured interview sessions (each 1.5 to 2 hours) with two interviewers (Drs. Widerström-Noga and Anderson). After the completion of each session, we will ask each subject if they want to add additional information to their interview. The interview will be taped in its entirety and transcribed verbatim. We will conduct face-to-face, semi-structured interviews using an interview guide with probes to ensure sufficient uniformity across the interviews.

We have to date completed the interviews for 14 people and conducted part of the interviews with an additional 7 people. The transcribed interviews are being reviewed on a continuous basis for content by Drs. Widerström-Noga and Anderson, and then discussed with regard to clarity, meaning, and preliminary themes. Part of this continuous process also involves Dr Martinez-Arizala and Perez.

Ten transcripts have been entered into ATLAS.ti and transcripts coded independently based on the areas of interest proposed in our Specific Aims. Dr. Widerstrom-Noga and Anderson regularly discuss themes and codes as new themes emerge. These first and preliminary codes have also been reviewed with our other Co-investigators. Below is our interim preliminary analysis and a summary of our results.

The interim analysis includes both factors that make life more difficult (barriers) and easier (facilitators) for those who experience SCI and chronic pain. Our preliminary thematic analysis address our Specific aims and includes the areas listed below. Please note that each area listed below may contain both barriers and facilitators and significantly overlap and interact. As this process goes on and we enter more data, we expect to discover additional themes, refinement, and changes in existing themes.

***Specific Aim 1A: To explore the perceptions of individuals with SCI and chronic pain regarding barriers and facilitators for living and coping with pain and SCI.***

***Specific Aim 1B: To explore the perceptions of individuals with SCI and chronic pain regarding barriers and facilitators to activities and participation.***

***Specific Aim 1C: To explore the perceptions of individuals with SCI and chronic pain regarding the barriers and facilitators to pain relief from treatments and self-administered remedies, and the role of social support.***

Thematic areas:

- I. Pain aggravation
- II. Coping with pain
- III. Self-remedies to reduce pain
- IV. Experiences/attitudes to treatments & clinical trials
- V. Access to pain management
- VI. Education
- VII. Social environment
- VIII. Pain Impact

**I. Pain aggravation**

This area contains various factors that aggravate pain in this population (e.g., disruption of routine, emotional distress, movement, prolonged sitting, spasms, temperature, and touch). Most commonly, people describe that their pain is worsened by mechanical stimuli such as light touch, sudden movements, spasms, and pressure from prolonged sitting. Below are some examples of quotations representing these areas.

***Quotations (out of 24):***

“It will give me like a tightness, I tighten, it will tighten up and I be like hold on don’t **touch** me right now, or I can’t move right now, I do that all the time, don’t move or touch me right there. A little rub will set it off sometimes. My wife she might touch me or rub me, I don’t do that, don’t touch that spot and it will come.”

“And um, the pain is you know, even any slight **movement**, you know, I, I , um it’s been a long time since I’ve had Charlie Horses but, you know, I know I used to get them a lot when I used to get dehydrated playing sports but, you know the **spasms** are up to that point, so I try not to do too much movement so it



just won't like lock in that position and that's pain that you can't really do anything about until that muscle relaxes. So I try to do as less movement as I can. So I don't know if I answered the question but I um, yeah okay cause they, they like go hand and hand."

"sharp pains like when I would turn a certain way. I don't know if it was because I was restless and maybe the way I moved and I like to lay on my left side, that's my most comfortable, I don't like to lay on my back I don't like to lay on my stomach. But like I laid on my left side but then I twisted like my upper body to where it was kinda flat on my back but my side was still twisted so I think that did it. But then when there was a lot of rain I had a lot of the pain and stuff and like if I over did myself like again cleaning the house and what not and then um the last couple of weeks before school started I watched my neighbors five year old so ***I would stay up in my chair all day*** and then of course not getting up or putting my feet up or anything because you know he is very demanding"

## **II. Coping with pain**

This area contains themes regarding different ways that people cope with their pain (e.g., using distraction, planning, positive thinking, praying, resilience/minimizing, worrying). People use *different* combinations of coping strategies to cope with their pain; there is also a great deal of resilience. Common ways to cope include distraction, praying, and ignoring pain. Below are some examples of quotations representing these areas.

### ***Quotations (out of 74):***

"So if it hurts, it hurts! Mm you have to ***grin and bear*** it sometimes"

"I ***prayed*** so long for that and um, and I happened um... I get a lot, I get frustrated a lot, you know but..., you know I have to be thankful... that, you know uh, I do have access to a place to lay my head, hot water and food and even though I can't do the stuff that I used to do, you know uh... I get frustrated, I get depressed, but then I have to think of where I was and where I'm at now you know"

"I go through a lot of pain in my back, in my stomach.... I deal with it, you know what I'm sayin' ***I won't let it stop me***"

"***I deal with my pain*** all the way, all the way I don't, I don't like taking pills, I don't like none of that"

"I'm in constantly pain. From the time I wake up, from the time I got to sleep. It's just, ***I just tolerate it I put it to the back of my head*** cause I know I have to get stuff done"

"I try just to um... you know, just to forget about it. ***I try to focus on um, my mind on something else*** you know. Um... other than that you know, nothing else I do um... nothing else I do other than try to focus on something else."

"my hands is constantly, you know what I mean, that's pain all the time. Um I try to tell myself that it's there so get over it you know what I mean? It's not going nowhere so you know... ***I try to deal with it***"

"To me pain is more of a mind thing. Its, I can really control most of my pain by, by putting myself in another place when the pain actually occurs. I try to think about something else, or something that may aggravate me more to ***distract me from the pain*** so that helps me a lot for the pain that I do get, for the period of time."

“it’s a constant so you just gotta, you gotta *distract yourself* I assume. Sometimes it works, sometimes it don’t work”

“It’s like your *worrying*, if you, am I going to be able to finish this project or if you will be able to you know, and you kind of expect it to start at certain time and it’s not starting, I say well I’m going to have a good day and then as soon as I say that it starts, so, your kind of waiting for it to happen, when am I going to have, when is it going to happen.”

“And sometimes yes I’ll *push myself* through it until, until I can’t anymore.”

### **III. Self-remedies to reduce pain**

This area contains themes regarding things that people do themselves to reduce pain (e.g., being in water, laying or sitting down, massage, movement, music). One of the most common ways to reduce pain is by laying down or changing positions. Below are some examples of quotations representing these areas.

#### ***Quotations (out of 21):***

“When the weather is good, we do have a pool in our apartment building and we’re off of the bay so when my husband is not working, we do go *swimming*. And that I has, have noticed has helped”.

“if I *move position* of my actual whole body part it has helped a little bit”

“some things that I can’t change and are, my legs are hurting real bad and I can’t do something I *just lay down*. I just try not even thinking about it, just *listening to music and just letting it go away*.”

“I try to um, first thing I do is *lie down* you know and put a heat pad on or I go to the clubhouse and go to the *Jacuzzi* which is the hot water that’s the best thing for me.”

“I still have some dull aching pain most of the time and if I it is gets worse, I do I *lay down* or I uh... laying down usually helps and if I’m sitting down, *standing up* “

“It’s only when I get to *moving* that, you know I’m relieved of the pain, but it takes a while.”

### **IV. Experiences/attitudes to treatments & clinical trials**

This area contains themes that are related to facilitators and barriers to participation in clinical trials (e.g., design, altruism, preferences, recruitment) and to obtaining pain relief form treatments (e.g., adverse effects, fear, insurance, lack of knowledge, no effect, time consuming, benefit, low risk, recommendations, routines). Moreover, thoughts regarding risk-benefit were common considerations both with regards to clinical pain trials and to pain treatments. For clinical trials, there were preferences for non-invasive and non-pharmacological treatment modalities and altruism was a motivator for participation. Common thoughts regarding barriers to participation included fear of side effects or deterioration. One important determinant for participation in clinical trial was the ratio between risk and benefit and availability of relevant information regarding this. Below are some examples of quotations representing these areas.

## ***Quotations (out of 103):***

### **Clinical trials**

#### **a. Facilitators**

“We gotta **help somebody** somewhere, sometime and if I can help somebody else get, you know, know something that they, they need to know then...”

“**acupuncture**, I think that would work”

“it’s physically I think **exercise** to me. To me it feel like that because before my accident, I used to exercise a lot. And that made me very depressed to see how active I was and, and I’m practically zero now.”

“Well, if it, if you know obviously it would give me an opportunity to uh, you know make the pain better. I mean, like I said it’s a risk factor but you know, I mean at this point **anything that is going to help** to you know.”

“That’s why I was saying I was considering like the acupuncture. You know **anything where I, I don’t have to take any type of medication.**”

“I would definitely would be interested because there, you guys wouldn’t be doing this if there wasn’t some type of guarantee you know, even if it’s maybe ten percent, cause **every little percent is, it’s something.**”

“Anything that’s harmful. If it’s going to be harmful, a major risk to it I won’t do it. If it’s something that could **benefit me and another person** I’d do it. If I could just benefit another person and don’t harm me, I’d do it.”

#### **b. Barriers**

“Concern another but, probably uh other... modes of medicine probably yeah but I don’t, **I doubt it for another surgery**”

“I know meds are not the answer. You know even though uh... I rely on them now you know um... you know **with medication always comes side effects** so...”

“yeah **I wouldn’t want to take the risk, and it might get worse** and... naw”

“you don’t want to think, you know the pain there but you don’t want to think it’s, it’s all in your head. And like somebody give you a **placebo**”

“I would be more for the acupuncture or you know massage. You know possibly if there was a medication or something I would try it but you know depending on the risk that come along with it you know because I already have existing health issues like my blood pressure. And you know osteoporosis or you know bone density issues, I wouldn’t want it to affect those things and make me worse. So you know it would be considerable **depending on the risk.**”

## **Treatments**

Participants rarely achieved substantial pain relief from their current treatment but sometimes described some benefit that allowed them to function better. A commonly held perception was that medication did not help and that medication was not worth taking due to unfavorable risk benefit ratio.

### **a. Facilitators**

*“the only thing that works for me is the oxycodin, Percocet, that helps but you know that’s temporary too”*

*“I complained enough until he actually gave me **a dose high enough** to keep me where I could stay at my daughters practice long enough without aching real, real bad. So, that’s all it does, I told him, **it just gets me through the day**. I take half, I don’t wanna take a whole, so, and I’m content with that. Cause they get, like you said, side effects constipation, addiction and all that, so.”*

*“That would be great if you didn’t have to take medications. To do **other treatments** as far as anything besides pills and shots and stuff like that would be great.”*

*“if you were to tell me that there was something going on for, like a treatment for pain **I would wanna read about it first**. Cause I like my legs healthy you know, I don’t wanna take any kind of drugs that’s going to make me not eat, or you know like make my legs skinny or just effect anything I don’t want you know disturb the tempo. I just, if it’s hurting then it’s gotta hurt you know, I feel like it’s worth it.”*

*“they gave **me another medication recently for inflammatory** which is helping and I have been only taking it for a week, so that’s helping me”*

*“I got **the medication now to control it**, it won’t take it away, but it will drop it from eight, seven to four or five, which I can deal with”*

### **b. Barriers**

*“I have been prescribed Darvacet but that **didn’t do anything for me**. I mean I’ve taken ibuprofen and it helps but temporarily and of course you **don’t want to keep popping** you know every four to six hours you know I don’t want to do that.”*

*“they will ask how I feel and I will explain that yeah I have pain here and here the burning sensation. I’m sure I could have ask again about the neurontin especially now that I know that it does takes the time but again I **just don’t like taking medicine, I just, it’s too much**.”*

*“**addicted to narcotics, pain killer narcotics** you know, I know that’s not a good thing either”*

*“**No more surgeries**, no more surgery”*

*“But I can’t, I **don’t want to be dependent on them** every day or whatever, I have them once every two weeks if that. I try to stay off of them cause I know that they work for me but it has side effects to, my stomach it constipates me. It’s workable but it’s, you have to be very desperate to.”*

*“Well... I don’t know... they (medication) all **mask something worse** I think. But uh... but without ‘em I think I’d be doing much.”*

“they wanna give me more but *I don’t wanna take anymore*”

“No, no, cause *then you REALLY don’t wanna do nothing*, the pain went away, but I don’t wanna get out of my wheelchair, I don’t wanna go outside... “

“*Sometime the medication work, sometime it don’t.* “

## **V. Access to pain management**

This area contains themes related to barriers and facilitators to pain management access. This area includes the following codes (e.g., not using, communication, scheduling and billing, clinic type). One of the common perceptions in this cohort was that their healthcare providers did not understand or deal their pain adequately and that personal engagement from their healthcare provider made a big difference. Below are some examples of quotations representing these areas.

### ***Quotations (out of 30):***

“*I don’t call a doctor for pain* or nothing like that, no”

“No *they don’t understand*”

“*I don’t think they deal with it.* They just try to write another prescription. That’s what they did”

“It’s not very difficult; *I just make an appointment and see a doctor*”

“Well... um... I have a new doctor now. And um, you there’s been a couple of times recently that um, my appointments have cancelled, I didn’t get to see the doctor, Um... on um... well this new doctor I made an appointment on 3, 3 occasions to where I only got to see her once; the other 2 times the appointment was cancelled. And um... I just got the feeling that you know what I’m saying... like you know what I’m saying, *the new doctor the understand is not like my old doctor* you know”

“*I tried to tell her about my pain* you know, and it was just like... you know I came in she didn’t really feel what I was saying to her “

“*you will spend a whole day here and by the time you go home you’re in pain and you didn’t get resolved* what you needed to get resolved or your halfway through and you’re in the financial aid process and you don’t have this amount of you know information or you made too much money and then you got to pay out of pocket ok well I just paid a weeks’ worth of bills with my paycheck and I can’t pay you right now, oh well then come back”

“*I feel like it’s great* cause I don’t run into any, too many obstacles’, or no problems, the insurance always be right and you get to pick and choose where you want to go at to get treated and so I’m comfortable with the people I been dealing with forever, so. And to be honest I can’t find if I have questions or problems I can’t go nowhere but here or maybe my therapist and them I can ask”

“my primary care doctor *don’t have no clue about no spinal cord injuries or no pain* in that area or spasms. All they know is medications “

“They respond on a, how do you say it, as normal. Uh, what’s the word I’m looking for? Routine. As a routine pain. I got a pain in my back they just think oh average pain as far as they ain’t gonna think oh it might be related to your spinal cord, your nerves, and its deeper than just exterior pain, you know? And

they won't look into it, look into as that. They will just say ok, we gonna give you this, you know, take this patch, you know? Instead of asking real questions as far as how long, or what started it, how I feel and you know? ***They need to go more in depth.***"

"Pulsating and its uh very debilitating when you have that pain, you can't sleep. Now I have sleep apnea so I'm going through a lot right now with the pain issues. But um ***the VA's got me uh stable right now*** so the pain is not as severe."

## **VI. Education**

This area contains themes related educational needs and preferences regarding pain and pain management. This area includes the following codes (e.g., healthcare provider, person, patient, research subject, and sources of health information). Many persons feel that education and information regarding pain and pain management is needed and they frequently search online for this. Some think that their healthcare provider does not possess adequate knowledge regarding pain. Below are some examples of quotations representing these topics.

### ***Quotations (out of 35):***

"Education, yeah, you know, cause um. Yeah I, I have been thinking about that, I have thought about that several times, um, ***I would like to know a little bit more about the pain*** and you know and I, I can combat it right, you know what I'm saying. It might be something I'm just overlooking and I could deal with the pain even better you know but you know it just ain't came to me yet, and, and education, to know exactly um about the pain, you know, just like it just explained to me about you know what I'm saying."

***"I like to go online and like research a lot of things"***

"Yeah we talk about it all the time. I'm so motivated and interested in, ***I have so many questions, I look it up***, I, we together on it, so. It's intriguing in a sense, because it's something new and different, but yeah we talk about it a lot and try figure out different ways to work around it."

"I, it really worries me as far as my age when I grow up ***what I'm gonna feel***. I wanna know a person that's a T6 level like me and if you 45 like what happened from 30 to 45, did it get worse or was it always going to be the same, was it going to be like this all the way? You know, I wanna know that."

"You know, they (healthcare professionals) you know ***they just ask questions***, oh that hurts? Why do you think that hurts? What do you do for that?"

"I mean I heard a lot of different things like when I first got injured. And then, like, oh my feet are burning, my feet are burning. ***I ask the doctors why, you know, I ask the nurse why*** and a lot of, most of the times they just give me a blank face and don't answer."

"Why is it my feet, why is it my buttocks? ***I definitely would like some answers.***"

"I don't, ***I don't know anything.***"

"I, I had never given it a thought that there would be studying, you know, solely concentrating on the spinal cord. And when you got up and talked about the pain and saying that it was lower, usually you would feel the pain lower than um, where your injury was. That opened my eyes; I said ***I never heard about***, this is something I have to."

"Although, now, if, if it hurts there's a reason, there has to be a reason behind it, ***why is it hurting?***"

“Cause a lot of times you go to your doctor not being a specialist and now you have to go to your PCP first explain what you had depending on your insurance and then go to your specialist and the specialist, it’s not that I’m against medicine; sometimes its *hit and miss*.”

## **VII. Social environment**

This area contains themes related the social environment and its positive and negative influences. This area includes the following codes (e.g., demands by significant other/family, do not understand, nobody to talk to, not comfortable talking about personal things, significant other/family worry, family and friends). Some people perceived that their pain was “invisible” to others. Several people relied on the social environment to cope with pain but worried about the burden they imposed. Below are some examples of quotations representing these areas.

### ***Quotations (out of 41):***

“this, I guess this is *an illusion* to them. They, they, I guess they think that okay that’s just, he’s just standing him up”

“I *never talk about my pain* to them”.

“Well like with my husband I, you know I talk to him to get it out as with anything in life. But I don’t want to say it’s not that he doesn’t understand *I just don’t think he understands the ex., what do I say extent of it...*”

“It *worries* my significant other, it worries my girlfriend. My kids cry when they see me hurting”

“She there for everything though, yeah. *She make it a whole lot easier.*”

“No they play a role as far as keeping me up and motivated cause I feel like ok I’m the oldest still. So they still look up to me, I still can talk to em, tell em and that was one of my things, is I was going to use this injury, you know to show other kids this ain’t the way to go or I could use this jury to show people you got this same thing uh how to be motivated, don’t be depressed or there’s always something else to do, *you know just don’t just lay in your misery, you know so, I’m just gonna, I’m gonna use it.*”

“No, yeah we talk, we, we discuss it, cause I ask her, because I don’t want to overwhelm her so I always ask if it’s getting too much to let me know you know *trying to keep communication going on.*”

“a lot of things that people, the average person really wouldn’t know like, like little stuff, your feet burning, you know the average person walks all day, their feet doesn’t burn, they don’t they, you know, they wouldn’t know cause you sit down in a chair all day *they wouldn’t know if you have any pain in your legs or anything* “

“I’m the type of person *I don’t really talk to anybody about like any of my issues you know*. I try to think of it like I’m a grown man, I handle everything on my own, you know. If I have a problem I fix it. “

“My support, my support is there you know *they understand when my pain is high they understand when my pain is low.*”

## **VIII. Pain Impact**

This area contains themes related the impact that chronic pain has on multiple aspects of life. This area includes the following codes (e.g., life, mood, participation, physical activities, sleep, work). Pain significantly impacts and disrupts multiple aspects of life. Below are some examples of quotations representing these areas.

### ***Quotations (out of 57):***

“Well... its.. (Sucks teeth) uh... it’s... uh kinda ***limits the things that I can do*** because you know I just don’t do ’em because it hurts! “

“it limits, what I can, what I do. It does. Uh... you know ***I try to do everything in one trip*** if I’m gonna do it. That way I’m only out of the house one time. And uh... I hate riding the bus and stuff but... (sigh) sometimes I have to. “

“***if I could get rid of some of the pain in my back, I would be, I would be, I would be happy. Happier*** I would say”

“Sometimes yes, yep (mumbles) ***sometimes I just don’t feel like doing anything*** it’s just I...The pain’s there and it just.... (mumbles) “

“***yeah the pain, the pain take a lot from my life. it, it really take a lot from my life***”

“ You know I get, ***it depresses me some times because the pain limits me doing the things that I, I wanna do.***”

“sometimes it can become overwhelming to, you know what I’m saying the pain, but um like I say I keep telling myself ***you have to keep going***, you have to keep going”

“Well-being that I’m not working, I would like eventually to get out. I was working in the past but I had to relocate and the, the, to travel back and forth it was, ***there was no way I would be able to tolerate it*** because of pain.”

“Major impact, because my daughter runs track and we go every Saturday from eight in the morning until at least four in the afternoon. And all I do is sit in the chair I don’t move, I just sit in the chair and watch the whole day and yes I have to leave and go sit in my car just to relieve my pressure and relax, for my back to relax and it cause a major problem. Sometimes I actually leave early because I just, ***its just unbearable to sit right through my pain***, it unbearable sometimes.”

“Like I can say for instance I want to be out here with my friends, like last night for example, I was out with my friends at my house, we outside ***watching the basketball game, everybody but, I got so much pain and the wind blowing I’m over here going ah I wanna stay out but I can’t.*** So it’s affecting me more mentally than physically, I’m like I’m just going to go on in cause I can’t take it.”

## **KEY RESEARCH ACCOMPLISHMENTS:**

### **Year 1**

- All administrative tasks and logistical study related issues (database setup, training, etc.) successful.



- Successful recruitment of individuals with SCI and chronic pain.
- Significant amount of data collected regarding issues of critical importance for individuals with SCI.
- Positive responses from research participants regarding the study (some have never previously been asked about their pain or talked about their pain in depth).
- Interim analysis performed.

#### **REPORTABLE OUTCOMES:**

An initial analysis of the emerging themes was recently presented at the 2013 Annual Scientific Meeting of the American Spinal Injury Association (ASIA), May 6th – 8th in Chicago, IL. This initial analysis was orally presented by Dr Widerstrom-Noga.

#### **CONCLUSION:**

We have identified 8 overarching areas consistent with our aims. Each of these areas includes several themes. The main areas are compatible with a biopsychosocial perspective of pain (i.e. pain aggravation by physical, emotional & other factors, coping with pain, self-remedies to reduce pain, experiences/attitudes to treatments & clinical trials, access to pain management, education of patients, community, healthcare, sources, positive and negative social influences, and pain impact on life, mood, physical activities, sleep, and work.

Our first *preliminary* model for the data collected in the present study is illustrated in the **Figure** below. The specific details of this model will be refined consecutively during the course of the study in parallel with further analyses. At present, we suggest that impact of pain determines the experience of living with SCI and chronic pain. The impact of pain is determined by a combination of *biological factors*, including injury and pain types, demographic factors, and pain-related factors; *psychological factors* including individual coping strategies and self-remedies and experiences and attitudes regarding treatments and clinical trials; and *social factors* such as access to treatment and information, and social environment. At the conclusion of this study, we expect to arrive at an integrated model for living with SCI and chronic pain that not only defines critical relationships among domains and barriers and facilitators to successful living, but also considers the immense diversity of this population.

## Preliminary Model for Data Collection

